Ethics and engagement in scientific communication

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The information related to science, technology and, especially, biomedicine, attracts increasingly the attention of the media, not only because of the growing interest on the part of the public, but also for the economic growth of the sector or the spectacular nature of the advances obtained in the last times. In this context, and due to the characteristics of the information to spreading, the scientific journalism has to assume the challenge of guaranteeing the rigor of the information and the accuracy of the contents, as well as a treatment of the news as objective as possible.

Keywords

Science, biomedicine, quality information, scientific communication, journalism ethics

Over the last few years there has been a considerable increase in the attention paid by the media to themes of science and technology and, most particularly, biomedicine. This increase may be attributed to three key factors. Firstly, the growing interest in this kind of news on the part of the public, as different market surveys have shown that the subjects of biomedicine and science have gone up the ranking in terms of public preference. On the request of press editors, a study carried out by the Spanish Centre for Sociological Research shows, for example, that the health and biomedicine supplements come second in the list of most-read.[1] In a special edition of the Eurobarometer published in 2007 on which news items interest European Union citizens most, those related to scientific research came fifth, with 31% of the preferences.[2]

Secondly, science in general and biomedicine in particular are among the most dynamic and fastest growing sectors, with millions of professionals interested in learning about anything new as quickly as possible, not just in their own area but also that of science in general. These are particularly demanding receivers, accustomed to working under highly competitive conditions and with a methodological rigour which they also wish to see reflected in the news products they receive.

The third factor that explains the growing interest in news lies in the spectacular nature of advances occurring over the

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1 CIS. *Estudio n.º 2.537. Hábitos de lectura de diarios*. September 2003. <http://www.cis.es/cis/opencms/-Archivos/Marginales /2520_2539/e253700.html>.

2 EUROBARÒMETRE. *La investigación científica en los medios de comunicación*. Brussels: Eurobarometer, 2007. No. 282. <http://ec.europa.eu/public_opinion/archives/ebs/ebs_282_en.pdf>

last few years. We have still not finished exploring all the paths for organ transplants, with face transplants being the latest landmark, but we can already find the first bio-artificial heart built with tissue engineering techniques. Human cloning is resisting but it's very close and while a probe is exploring the surface of Mars and is sending us images of an impressive quality, terms such as quantum computation, proteomics and nanotechnology appear increasingly more often in the pages of newspapers.

Guaranteeing the rigour of information, the accuracy of content and the objectivity of treatment of news items is the great challenge facing scientific journalism. In fact, these are the great challenges of journalism in general, but in the case of scientific journalism the difficulties that must be overcome are very specific and not always easy to identify. In these times, when the word *fast* impregnates everything, from *fast food* to *fast thinking* and *fast living*, we can also see growing pressure for fast, brief, easy to consume information. But if there is an area where information cannot be fast nor brief if we want to achieve a minimal level of quality, that area is science.

One of the elements that has most changed the so-called media society is how scientific knowledge is socialised. The media have become the main instrument for transmitting new knowledge. Now, discoveries and advances are communicated at the same time to the scientific community, via their specialist journals, and to the public at large, via the media. Scientific journals' capacity to impact is no longer measured only by their penetration among researchers but also by their capacity to catch the attention and news space of the general press.

Before the media society, scientific knowledge followed pre-established itineraries via official institutions. When this knowledge finally reached the public, it had passed through various verification filters and had had time to settle, making it much more secure. When it was finally disseminated through, for example, the educational system, it was relatively well established knowledge. Now, scientific knowledge goes directly from the laboratory to the public, which has its advantages but also its drawbacks. It is true that this allows us to rescue it from some elites that often used to use it for their own benefit, and that direct disclosure empowers the public, i.e. their decision-making capacity. But the knowledge that arrives via the media is, by definition, provisional knowledge. There has often not been enough time to validate it and it is frequently modified, corrected or directly refuted in later stages. The episode of false human cloning on the part of the Korean scientist Hwang Woo-Suk is the latest and most infamous example but not the most important: newspaper archives are full of new treatments that have promised to cure illnesses but which continue without any possibility of cure.

In spite of all this, the scientific method provides science with a plus of credibility that also benefits the media in their work as disseminators. This is what is allows Furio Colombo[3] to state that scientific news travels through news space with a huge load of added value, which makes it attractive and dangerous at the same time: attractive because it contributes towards the prestige of the medium and helps to increase reader loyalty, and dangerous because any error in this area can wreak havoc on the medium's credibility.

Precisely because science advances thanks to the empirical method, in scientific communication speed is usually inversely proportional to certainty. On the other hand, the internet and networking has encouraged exponential growth in data and information in circulation, something which makes validation even more difficult. If, today, even for scientists themselves it is difficult to remain up-to-date with everything occurring and published in their specific field, it is just the same for the media, which attempt to cover all fields and, moreover, to do so with such speed: very often the production time for scientific information is no longer than a few hours. "What makes a piece of news valuable is the number of people likely to be interested in it, [...] but also the speed with which it is disseminated. If you have some information and take one month to disseminate it, it loses a lot of its value. The question is: what is the plausible degree of speed? Today it is instantaneousness and it is evident that instantaneousness involves great risks", warns the journalist Ignacio Ramonet[4].

How to distinguish, from among the huge amount of

3 COLOMBO, F. *Últimas noticias sobre periodismo*. Barcelona: Ed. Anagrama, 1997. (Col. Argumentos), p. 96-111.

material produced, what is truly important and represents an innovation or a leap forward is one of the main challenges of good journalism. The circulation of information has grown exponentially, to the point that, at this time, newspapers with thousands of pages could be produced with just the material that reaches newspapers directly, provided by the different interested sources. How can rigour be maintained under these conditions? And, above all, how can we identify the hidden agendas that are often behind the information that arrives? Knowing the risks surrounding information is the prior requisite to being able to tackle good information from an ethical point of view. Only by knowing the nature of the possible traps can we arbitrate defence strategies and mechanisms to neutralise them.

As in all professions, among journalists there are also cases of professional malpractice that must be energetically fought via internal, self-regulating standards. But these individual cases are not the ones that are habitually behind many of the misrepresentations that occur. These are often the consequence of news dynamics that affect all media and disregard the will of journalists themselves, especially if they are not vigilant. We might say that, today, as always but perhaps more than ever, a prime requisite for ethical journalism is to have an active and permanently critical attitude, which means questioning both the data that arrive as well as the sources providing these data.

Guaranteeing the ethical quality of scientific news requires precise knowledge of the risks and challenges inherent in this kind of information. Firstly, we must tackle the certain tendency to exaggerate and sensationalise. The media often allow themselves to be contaminated by the hagiographic approaches of the scientific community itself, which increases their potential with exaggerated qualifiers. Given the nature of the sources and the material in question, scientific news is one of the most susceptible to becoming what Furio Colombo classifies as news-reverence: "The natural resistance to investigate that is spreading throughout contemporary journalism is not only reinforced when the source is scientific but tends to present it as absolutely sure", he says.

The tendency to sensationalise generally makes itself known in two ways: by increasing the number of news items published not because of their importance but because of their capacity to cause impact, and with a treatment prone to emphasising the most vociferous aspects in all kinds of information. This tendency, the result of competition between the different media, is also contaminating scientific journals. In the entrenched battle maintained for two years by the journals *The New England Journal of Medicine* and *JAMA*, the latter was often accused of taking the possible media repercussion too much into account when choosing the subjects it published. In 1999, George Lundberg, the director who, over 17 years, had converted a simple internal newsletter of the American Medical Association into a leading scientific journal, was finally dismissed. The reason was because he had published research of doubtful scientific value on oral sex, based on data obtained years previously, coinciding exactly with the impeachment trial against President Bill Clinton for having lied regarding his sexual relations with the intern Monica Lewinsky.

Days before, scientific journals provide the media with brief notes on the work that will be published. Studies carried out on these press releases show a tendency to select those subjects with most potential to attract the media's attention. The tendency towards sensationalism also often contaminates the activity of social actors themselves, who resort to spectacle to catch media attention. Anders Hansen[5] and his team from Leicester University have studied this phenomenon in organisations such as Greenpeace, which has gone from being a small group of locally-based activists to a multinational ecological corporation capable of affecting the political agenda thanks to its "astute publicity" and the intelligent use made of the media's tendency to sensationalise.

Since, at the end of the nineties, two scientists from Utah University, Pons and Flechsman, announced in a global

4 RAMONET, I. *La tiranía de la comunicación*. Barcelona: Editorial Debate, 2003, p. 56.

5 HANSEN, A. *The Mass Media and Environmental Issues*. Leicester: Leicester University Press: Centre for Mass Communication, 1993. HANSEN, A. "Greenpeace, el éxito de un grupo de presión ambiental". In: *QUARK*. Barcelona: Observatori de la Comunicació Científica (Universitat Pompeu Fabra), October-December 1995.

press conference and also in an article in the journal *Nature* that they had achieved cold fusion with deuterium, in what was considered one of the most scandalous frauds, various teams have successively fallen into the same trap and the same ridicule. Among them, the University of Valencia, which held a hasty press conference to present the work of a team that had supposedly found a way to easily obtain energy from water. The fear of being copied led them to announce this supposed discovery to the press before the scientific community and, in the excitement of the moment, one of the scientists raised a small bottle and said that, with that water, enough hydrogen could be obtained to go from Bilbao to Valencia

Many of these fiascos are the consequence of the ferocious competition between teams. The fear of seeing yourself overtaken by a rival team was just what led the Korean Hwang Woo-Suk to falsify data from research into cloning, an area in which he was truly competent and which might have produced results. Not knowing how to wait led him, overnight, from glory to ignominy.

One variant of this tendency to sensationalise combined with the pressure to publish is that which, in biomedicine, favours the creation of false expectations. The craze to be the first and the need to legitimise research socially in order to obtain economic results is leading to scientific discoveries being published at increasingly earlier phases of the research process. They are the "futures" of medicine, the molecule that has just been discovered and is presented as the next treatment for an illness, without taking into account the fact that, in any case, this will only happen once it has been proven to be effective, first in animals and then in humans and, moreover, if it has no adverse effects, i.e. after ten years and hundreds of millions of euros, supposing that everything goes well. Many of these "futures" announced in the media never actually materialise. Rigorous, ethical information must avoid creating false hopes because it can cause frustration and suffering in the readers and because it can help to undermine the credibility of the media themselves.

It is even more difficult to guarantee the quality of information against a more insidious risk: the existence of hidden agendas or spurious interests in the information reaching the media. These are news items whose data, or how the information is presented by the sources, have been biased to achieve a non-declared aim. One of the best-known cases of this kind of distortion starred NASA when, in August 1996, it held a global press conference to announce that it had found evidence of life on Mars in the remains of a meteorite. The news, obviously, was on the front pages of all the newspapers in the world. Afterwards it was realised that this evidence was no more reliable than evidence which had already been studied and rejected some time before and that it had all been a set-up to force President Bill Clinton to rectify the announced cuts in the space agency's budgets.

Although not so spectacular, episodes like these are repeated with a certain frequency, sometimes to obtain resources, other times for prestige or simply for market objectives. One of the areas where bias can have the most serious consequences, due to the subject in question, is once again biomedicine, particularly with regard to new drugs and therapeutic procedures. In some cases, the danger lies in the possibility of information being published on new therapies with insufficient evidence regarding their properties.

How can the media guarantee true, accurate information for their readers? What mechanisms of quality control can be applied? It's difficult for the media to have their own evaluators for each and every specialty of medicine ready to evaluate at all times the latest discoveries from leading teams. They can have trustworthy sources they consult on specific matters but that isn't enough.

That is why those media that wish to be rigorous used the same control mechanisms as the scientific community: the verification of content on the part of solvent scientific bodies. In the case of medicine, this might take the form of publication in leading scientific journals such as *The Lancet*, *The New England Journal of Medicine*, *JAMA*, *Nature Medicine*, *Cell*, *Stroke* or *Proceedings*, among others. When selecting the work to be published, these journals use a peer review system, i.e. review by the best specialists in the area in question. Sometimes work presented at scientific congresses can also be considered as reliable, although, in this case, credibility is less due to the strong dependence on the industry financing them.

In the last few years, however, there have been a number of serious incidents concerning the safety of new drugs that have revealed that this validation system also has serious

deficiencies. The credibility of the pharmaceutical industry as a source of information has been damaged and the perception of insecurity has increased among citizens, which leads companies to present their new products through intermediaries, i.e. scientists that collaborate with them and that often do not declare this. News from the industry is now suspect, not only among journalists but also to a large extent in the scientific community.

Given that the media are frequently used to introduce and promote the use of new drugs and therapeutic procedures, it is an ethical imperative to carry out the utmost vigilance and even calls into question the work arriving from the most prestigious sources, with additional checking and a greater demand for transparency in the publication of clinical data. Achieving this is not at all easy. Globalisation has radically changed journalists' relationship with sources, so that many professionals today have the impression that their capacity to control what is published is less than before. In theory, all the information produced in the scientific world, wherever it is, is available for any journalist interested in it. There is a lot of information, more than ever, perhaps even too much. But what information is it?

Obviously, when a team achieves a spectacular breakthrough, its members cannot be personally available to the thousands of journalists from all over the world interested in checking the data with them. In these cases, the press services provide a good support, with popularised explanations of the habitually cryptic scientific language. This system works reasonably well in many cases and has helped to improve the quality of content of many written and audiovisual media that do not have specialist journalists.

But when the subject is controversial, the difficulty in accessing sources represents a serious risk to the quality of the information. When a particularly controversial piece of news breaks, and a decision has to be taken quickly, very often an insuperable paradox occurs: close, accessible sources do not have enough information for an evaluation (or they don't want to give an opinion) and the sources that have the information are not within reach of the journalist. Put another way: the well-informed sources are not available and those that are available are not informed. Very often, the only decision remaining to the journalist is whether to publish the information or not as it has arrived, without being able to access the details that may be relevant for the conclusions and therefore to evaluate and title the item. Sometimes these data are deliberately hidden. Opacity is the worst enemy of rigour in information and good journalism.

All interests may be legitimate, including, evidently, the desire of the pharmaceutical industry to get as much profit as possible from their products. Often the methods used to do so are not so legitimate. In recent years, changes have been seen in the marketing strategies of many pharmaceutical companies. The difficulty in obtaining new molecules and the high costs of research have led many companies to look for profit via other means. For example, creating new needs or achieving new indications for their old products. That is how we have gone from having ill people searching for drugs, to having drugs searching for ill people.

The growing medicalisation of natural processes, such as the menopause or the feeling of pain after a loss are, in part, a consequence of this new strategy. In this context, doctors are not the only target for promotional campaigns. Now it is also the public at large, and the way of reaching them is through the media.

The case of hormone replacement therapy is a paradigmatic example of this new dynamic and its serious consequences. Although, in the United States, hormonal products started to be prescribed at the end of the forties, their use was very limited. Suddenly, at the end of the eighties, newspapers started to receive dossiers and research studies on the huge disorders associated with the menopause and the risk involved of suffering osteoporosis and coronary disease. All the media published extensive reports on this issue.

That sudden interest was not, however, the consequence of new discoveries or the arrival of women in research centres. The true reason emerged a short time afterwards, with the launch of hormone replacement therapy, presented as a miraculous remedy for women. They didn't need to suffer anymore. I remember a press conference with the, at that time, heads of gynaecology from the main hospitals in Barcelona in which hormone replacement therapy was recommended as a preventative treatment for all women as from 50 years of age and for at least ten years. When the social security refused to finance it in general, some women's groups and doctors talked of discrimination. In reality, what women were being offered was eternal youth with a

drug that seemed innocuous. But what scientific evidence was actually available?

Hormone therapy was the object of great controversy for years until, in May 2002, the study entitled Women's Health Initiative[6] that was carried out with 16,800 women on the request of National Health Institutes in the United States to definitively evaluate the preventative properties of the treatment, had to be suspended although it still had three years to run. At that point it was already clear that not only did it not have the benefits announce ten years previously, but that the risk of ictus and breast cancer increased. From that moment, hormone therapy returned to the place that it should never have left, i.e. a treatment that might be useful in certain cases but with a prior, rigorous individual assessment of the risks and benefits.

The case of hormone therapy is a good example of the new strategies to conquer the market. Firstly, the aim is to identify or create a new therapeutic need, the wider the better. Then to mobilise the social actors related to this need, basically patient associations and medical societies. And, finally, to colonise the media with news items produced by these agents on the solution being offered. Some of the most widely sold drugs in the last few years, such as Prozac (fluoxetine), Viagra (enalapril) or Serotax (paroxetine), that form part of the so-called "happy pills", have been a commercial success thanks precisely to this kind of approach. If in Spain there were really as many depressed people as indicated by the sales of anti-depressants (more than 20 million packs a year), we would have to be seriously concerned.

In spite of the fact that it has been marketed in Spain since 1992, paroxetine was launched to the "whole world" from London in 1999 as the "shyness pill" and, in the press releases, as a new therapy against social phobia. In its report to the AGM in 2000, 2000, Barry Brand, CEO of Glaxo-Smith-Kline, could not express himself more clearly: "Every marketer's dream is to find an unidentified or unknown market and develop it. That's what we were able to do with social anxiety disorder". He had managed to build a positive by dint of mobilising doctors and shy people to colonise the media. In 1999, the New York office of *PRNews* counted a thousand million mentions of Paxil, the trade name of the drug in the United States.

Sometimes, however, the fight to occupy the market can have serious consequences for patients, as demonstrated by the Lipobay case, a drug against cholesterol that was withdrawn in August 2001 when a hundred deaths had been notified. That of COX2 (selective inhibitors of cyclooxygenase) is the latest example and the most serious. In 1999 many newspapers published, with big headlines, the marketing of these new revolutionary anti-inflammatories that, unlike the old NSAIDs (no-steroid anti-inflammatory drugs), did not cause gastric problems. Quickly the new anti-inflammatories pushed out the old ones. Two years later, the first independent study was published that warned about possible serious cardio-vascular side effects. Merck, the pharmaceutical company that held the patent, counter-attacked by questioning the validity of this study. When, three years later, the drug Vioxx was withdrawn from the market because of adverse side effects, more than 20 million patients had taken it in the United States alone. In Spain, around 277,000. The US Food and Drug Administration estimated, in a study later published in *The Lancet*, that Vioxx might have caused between 88,000 and 140,000 cases of heart attack or serious coronary disease in the United States alone.

The drug is now facing 17,000 lawsuits and, apart from whether information was hidden on side effects noticed in the research stage, which is still highly controversial, what has been proved is that the clinical studies had serious deficiencies. For example, only 2.1% of the patients who took part were older than 65, when anti-inflammatories are prescribed principally for elderly people, whose arteries are normally in the process of arteriosclerosis.

This serious incident has brought into doubt the whole system of clinical research and the publication of results. Different articles published in scientific journals in later years have already shown the growing concern of the scientific community due to how clinical research is evolving. *The New England Journal of Medicine*, for

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6 American Medical Association. "Risks and benefits of estrogen plus progestin in healthy postmenopausal women: principal results from the Women's Health Initiative randomized controlled trial". In: *JAMA*, 17 July 2002. 228 (3): 321-33.

example, published in June 2000 a long article by Thomas Bodenheimer[7] based on a survey, carried out with guaranteed confidentiality, on 39 of the most eminent scientists from different specialties. They revealed themselves to be very concerned about the loss of control over clinical research, not only with regard to study design but also concerning the interpretation and publication of findings.

This loss of control is related to the growing role of the so-called contract research organisations (CRO), which are employed by pharmaceutical companies to carry out clinical research. They are the ones responsible for recruiting doctors and patients for clinical trials, often in third world countries where ethical requirements are less rigorous. CROs control the whole process, from the study design to the tabulation and publication of findings. In 1990, 80% of the clinical research carried out in the United States was done through academic institutions. Eight years later, the percentage had fallen to below 40%.

In September 2001, thirteen of the most prestigious research journals published a joint editorial expressing their concern about the deviation of clinical research and demanded more transparency in the conflicts of interests, more independence and more respect for scientists. Obviously, from the media's point of view, clinical research designed and controlled by hierarchical, transparent public institutions is, in principle, much more trustworthy than other research carried out by often opaque structures in the private sector.

Sometimes conflicts of interest occur not at the time of the research but in the marketing of the product. And, in this case, the media can also be involved. In the information society, being on the information agenda has become a prior requisite to being on the political agenda. Often dilemmas and controversies about whether new products should be introduced or whether they should be financed by public funds are settled in the media.

The recent approval of the vaccine against the human papillomavirus to prevent cervical cancer is a good example of this. Although the studies we have do not allow us to guarantee that the vaccine covers the whole life of women, nor that it is exempt from side effects in the long term, the decision has been taken to give it to all girls as part of the official vaccination schedule. In Catalonia, this means practically doubling the cost of vaccinating. Prestigious specialists in public health have questioned the decision as they feel it is hasty. There is no doubt that the vaccine can save many lives in countries where vaginal infection caused by this virus is endemic. But in Spain, the mass vaccination of girls (it must be administered before they have sexual relations) is a controversial measure, given the low incidence of cervical cancer and the existence of another preventative procedure, the cytology or Papanicolau smear test, which should still continue for decades because there will still be a lot of women who have not been vaccinated.

The aforementioned specialists estimate that, when the first death can be avoided thanks to the vaccine (in about thirty years' time), the public health authority will have spent around 4,000 million euros on vaccination campaigns. The question is: how many lives could be saved if this money were allocated to other measures, such as the early detection of breast or lung cancer? And how many PET-CT machines could be installed in hospitals to improve cancer diagnosis? It is not a question of exchanging some deaths for others. Without the vaccine, deaths from cervical cancer could also be avoided by simply improving screening with the smear test.

This is a good example of the growing complexity of the issues settled in the debates on public health, where often an attempt is made to direct social actors and public opinion towards certain positions. In this case, the strategy has followed an old tactic: the so-called "peer effect". The idea is to get some medical society to recommend the vaccine and some autonomous community to proclaim its decision to vaccinate, as done by the Community of Madrid, in order to achieve a domino effect on the rest. The same thing happened with the vaccination against meningitis by *Haemophilus influenzae*. What politician would risk being accused of not wanting to protect his or her teenagers?

But in debates on public health, it is not enough to

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7 Newman, T. J.; Bellin, E.; Bodenheimer, T. "Uneasy alliance: Clinical Investigators and the Pharmaceutical Industry". In: *The New England Journal of Medicine*. 17 August 2000. <http://content.nejm.org/cgi/content/extract/342/20/1539>.

determine the cost and benefit of a product or procedure. When the resources available are limited, it is an ethical imperative to think not only of each patient but of people as a whole, because sometimes a sick person can be deprived of something necessary in order to provide something that is unnecessary. For this reason, it is not only a question of new products proving to have a good balance from a cost-efficacy point of view but also from a cost-opportunity perspective. Some of the most widely prescribed drugs today would not pass this test.

If we wish to serve society well, if we wish to guarantee rigour and an ethical approach to the task of informing, the media cannot ignore the conflicts of interest that often lie behind the information published. I have already mentioned that all interests can be considered legitimate but very often the problem lies in how these interests are defended. And often their defence includes the manipulation or biasing of information. Given these challenges, both journalists and publishers have to have a very clear idea of where our loyalties lie: with our readers. On this clear idea depends our credibility, the most important asset in our profession.